

HANDOUTS FROM THE NOVEMBER 16, 2022



2 Peachtree St. NW, Suite 26-246
Atlanta, GA 30303
Main: 404.657.2126
Toll Free: 888.275.4233
Fax: 404.657.2132
TDD: 404.657.2133
www.gcdd.org

Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver
Plan Access
D'Arcy Robb, GCDD Executive Director Testimony
11.16.22

Good morning, members of the study committee. My name is D'Arcy Robb and I'm the executive director of the Georgia Council on Developmental Disabilities. Before I begin, I want to express my gratitude to each member of this committee – to your organizations – and especially to our bipartisan leadership. This group has heard some really hard testimonies from folks with disabilities, family members and providers. But hearing those hard truths in this setting brings me hope because this group is listening, and I believe committed to taking sustained, thoughtful action in a way that supports the disability community. I really appreciate each one of you for being committed to this process and this community – and please know that we here at GCDD, myself, council members and staff are here for you in partnership to help solve these issues together. And speaking of staff, I want to particularly thank Dr. Alyssa Lee on my staff who partnered with me in putting this presentation together and is here today, along with Charlie Miller our legislative advocacy director.

With that – as you can see in this presentation I'll be focused on sharing some statistics, some information on services as well as some recommendations for improvement.

First, I want to take a moment to acknowledge who we are at GCDD, what we mean when we say developmental disability, and take a moment to consider that against our NOW & COMP waiver criteria.

The mission of the Georgia Council on Developmental Disabilities is to bring about social & policy changes that promote opportunities for the wide spectrum of persons/people with developmental disabilities and their families to live, learn, work, play, and worship in their communities.

GCDD is a federally funded, self-governing organization charged with identifying the most pressing needs of people with developmental disabilities here in Georgia. As per the federal Developmental Disabilities Assistance and Bill of Rights Act, better known as the DD Act, over 60% of our members must be individuals with developmental disabilities or family members of people with developmental disabilities. That's really critical to who we are as a DD council – that our governance comes from our members – and the majority of our members are folks who are experts in developmental disabilities thanks to their daily lives – either by having a developmental disability themselves or loving someone who does.



As you can see here, it's defined broadly in the DD Act as a severe, chronic disability of an individual that could be attributed to mental or physical impairment or a combination of both; manifests before that individual turns 22; is likely to continue indefinitely; and results in substantial functional limitations in 3 or more of these areas of major life activity. We sometimes refer to developmental disability as an umbrella term, because as you can see, this covers quite a lot – someone with limitations in language, learning and self-direction will have a very different experience with their disability than someone with limitations in self-care, mobility, and capacity for independent living. But for all folks with developmental disabilities, the bottom point holds true – they need individually coordinated support.

On this slide, you see NOW/COMP waiver eligibility information for us here in Georgia. I'm not going to go through this with you piece by piece – but I did want to point out that this criteria is different – narrower – than the broader definition of developmental disability we were just looking at. One way to be approved for NOW/COMP is to have an intellectual disability – defined as, onset prior to 18 years old, significant limitations in adaptive functioning

And an IQ of 70 or below – and as you can see, there is some allowance there for an IQ slightly above 70. The other way to be approved for NOW/COMP is this “related condition” path – closely related to an intellectual disability. As you can see in the blue text at the bottom – the condition must impact the individual in such a way that the individual required treatment or services similar to those required for individuals with intellectual disability.

On this slide, you can see the additional requirements for eligibility through a related condition. The reason I show you all this isn't to scrutinize the eligibility criteria – but it's to point out that we're already setting a high bar to qualify for NOW or COMP. The downside of that, from our perspective, is that there are folks with a developmental disability who don't qualify for this kind of support because they don't have intellectual disability or a related condition. I think that would be a great conversation to have with this group long term – is how are we supporting folks who don't qualify for a waiver and yet need some support?

On the flipside, what this waiver eligibility says to me is, folks who have qualified for a waiver need that waiver. I realize there is a subgroup on the waiting list, I'm thinking of those in school, who may not need a waiver right now, but there is not a doubt that the support will be needed. I can tell you all honestly that in my years of doing this work, I can't think of a single time when someone has been approved for a waiver and there has been question about whether or not that person warranted that level of support.

I'd like to take a look at some statistics and services specific to the population of folks with intellectual and developmental disabilities – starting with, when we say Georgians with ID/DD, about how many folks are we actually talking about?

When we do some of our federal reporting at GCDD, we are required to cite the top number here – approximately 170,640 Georgians with ID/DD. I want to point out that this is a number, from the mid-90's. We think it's more accurate to look at state of the States in Intellectual and Developmental Disabilities, which is a longstanding, annually updated, reputable source of data on folks with intellectual and developmental disabilities. According to State of the States in 2022, there are

approximately 226,000 caregiving families supporting someone with intellectual or developmental disabilities here in Georgia.

If we've got approximately 226,000 folks with intellectual or developmental disabilities being supported by their families, and 3.8 million households in Georgia, we can estimate that about 6% of families here in Georgia are providing care for a family members with intellectual or developmental disabilities.

You can see our waiver numbers are much lower than that. As of this August, we had over 13,000 folks receiving NOW/COMP waivers – and over 7,100 folks on the waiting list. You might be struck by a couple of things here. One is that these numbers are significantly lower than the estimate of how many folks have ID/DD. I think it would take some time and careful analysis to tease out exactly why that is – but part of that reason goes back to our waiver criteria, not everyone with developmental disabilities would qualify. And then there's the question of - knowing how important and necessary these services are, why do we have a waiting list at all? Now the short answer would be funding, but we wanted to take a deeper look into that.

This slide shows data from State of the States looking at fiscal effort – defined as state spending on ID/DD services per \$1,000 of personal income. As you can see from this slide, Georgia is low in terms of our fiscal effort spent on ID/DD services. At \$2.82, we are significantly below the national average of \$4.60, and we are low among our neighboring states in the Southeast, behind Kentucky, Arkansas, Louisiana, Mississippi, South Carolina, North Carolina and Tennessee. I share this slide because I think it gives some valuable perspective on why the waiting list has continued to be such a challenge for us in Georgia, despite the fact that only a relatively small percentage of folks with intellectual/developmental disabilities in our state are approved for a waiver.

This next slide also shows data from State of the States. If you remember the estimated 226,000 families providing care to a loved one here in Georgia – only 4% of them are getting state support. I think this tracks with what we've heard in terms of testimony to this committee and what I suspect you all have heard in your professional and personal lives – the majority of Georgia families out there supporting someone with intellectual or developmental disabilities are doing it without a waiver and without family support dollars, without formal adult DD services from the state.

So right now – who is paying, monetarily or otherwise, when it comes to supports or lack of supports for Georgians with intellectual and developmental disabilities? Georgia families. In the words of Dottie Adams, who was a beloved disability advocate, “Families give and give and give” – in some cases, till they have no more. Parents sacrifice their careers to support their children – in the sense of promotions and career downsizing and sometimes dropping out of the workforce entirely. I think we've all known parents who sacrificed their health – I know some families who've sold their homes for the funds in generates to support their children. Our providers are Georgia businesses and we've heard plenty in this committee about the unsustainable strain on those provider agencies, leaders and their staff. Finally, Georgians with intellectual and developmental disabilities pay the most of all – because when you need quality support to live your life and access your community and don't get it, it's devastating to that person and a loss to the community of everything that person has to contribute.



This recent quote about the situation of our disability services system by a provider really haunts me – that provider has spoken to me on a number of occasions about how families break. Specifically, “families have to break before they can get support. And usually in a way that hurts the person with disabilities.”

Now – how do we change that?

I believe part of the change is in our mindset. We need to not only look at developmental disability services as critical human services but as invaluable tools for economic development. When their loved ones with intellectual and developmental disabilities have support, parents and family members can continue working and advance in their careers. When our providers can pay employees a livable wage, they can add jobs, retain employees, and those employees put their money back to the local economy. Folks with disabilities can contribute to their communities when they have support, and this is especially viable if we craft our services using an Employment First approach. Employment First means that we look at paid employment as the first option for publicly funded day services for every person with a disability, regardless of the how significant the impact of their disability. Not only is this possible to do, it reaps tangible economic benefits for the state.

There are studies to back up these arguments. A 2021 study found that waivers benefit the economy by reducing unmet healthcare needs and allowing families to continue working. Another study by MetLife found that the national caregiving cost to business is an estimate \$33.6 billion resulting from issues like replacing employees, absenteeism, and unpaid leave.

Earlier I spoke about Employment First. When we invest in employment services for people with ID/DD, our state economy benefits. Specifically, there is a \$1.46 return on every dollar spent, resulting in a net benefit to taxpayers of \$251 a month and \$3,016 a year per individual supported employee.

I suspect other states are embracing waivers as economic development tools as well as critical human services. Several states in our region have recently announced major efforts to partially fund or even end their waitlists. At the end of 2021, Arkansas Governor Hutchinson announced his administration would end their 3,200 person waitlist and their legislature approved \$37.6 million to fund those waiver slots in 2022. In Oklahoma this year, the state appropriated \$32 million to fund their entire waitlist of 5,200 people.

Florida is making significant investments in waivers, appropriating \$95 million in 2021 to fund 1,900 waivers and almost \$60 million this year to move 1,100 people off the list.

Finally, several southeastern states are using ARPA funds to reduce their waiver waiting lists – Alabama, Florida, Mississippi, North Carolina and Tennessee.

Now – taking a look at us in Georgia. In our current SFY 23 budget, we have just under \$405 million for adult DD services, which includes waivers. Most of us, when we hear \$405 million, would say that sounds like a big number. But it’s also critical to remember – we’re looking at this in the context of a \$30 billion dollar state budget – and this chart shows us that adult DD services make up a bit over 1% of that budget. When you think about how 6% of families are supporting someone with ID/DD, about the level of fiscal effort in Georgia relative to nearby states and about the dire

need for these services that we've heard in this committee – I think that gives strength to the argument we need to make a greater investment in adult DD services.

Where could we get this type of investment? One place to consider is 2023 tax refunds. Last year, Georgia gave out \$1.1 billion in tax refunds, or \$250 a person. If each person had given up \$25 – that would have almost wiped out the waiting list. That would have funded 5,500 waivers. If we can communicate to Georgians the needs of these families and folks with intellectual and developmental disabilities – I believe just about everyone would willingly give up \$25.

We currently have a \$6.6 billion surplus and just 0.3% of that would fund 1,000 new waiver slots. Finally – we could look at the GNETS funding, currently at \$54 million a year. A reduction in this funding could go to annualizing new NOW & COMP waivers.

We have heard the need for more services throughout the meetings of this committee – and in terms of short term advocacy, here at GCDD, we are advocating for additional waiver slots. This coming session we are advocating for 1,000 additional waivers at a cost of approximately \$19.8 million. We also believe that this year, it is critical to increase DSP wages to a minimum of \$15 an hour, and that it would serve us well to update our long-term plan to address DD service needs, complete with benchmarks and funding strategies.

Medium to long-term, we are advocating:

1. End the wait list – fully fund NOW/COMP wait list and maintain a focus on ongoing waiver needs.
2. Keep DSP's at a livable wage to support Georgia families & businesses.
 - a. Participate in national conversation and strategies around DSP workforce.
3. Centralize Employment First in waivers and services
4. Work to maximize resources in a way that supports individuals with disabilities and their families
 - a. GVRA gives back federal funds - need to match & utilize these funds
 - b. Georgia's percentage of state spending versus Medicaid spending is high – consider how to wisely maximize federal match
5. Consider potential Medicaid care model changes with great diligence
 - a. Improvements in outcomes for Medicaid members should be the drivers of change
 - b. Intentional, well-designed planning & implementation, and the close ongoing involvement of the ID/DD community, is critical for any successful model change
6. Develop long-term, person-and family-centric service evaluation model to ensure HCBS services are appropriate and meaningful for Georgians with ID/DD and their families.

Again, I thank you all for your time, your passion for this issue and your commitment to the disability community. Please know that GCDD is here with you in partnership as we work together to make Georgia a better place for people with intellectual and developmental disabilities and their families.



November 16, 2022

Dear Members of the Senate Study Committee on People with I/DD and Waiver Plan Access,

We appreciate your work in leading Georgia to a better understanding of the issues that face individuals and families living with intellectual and developmental disabilities.

We are writing to introduce a newly formed disability coalition called Unlock 2.0. The mission of this statewide coalition is to advocate for greater investment in home and community-based services at the state and federal level for citizens with disabilities, and to ensure the quality and accessibility of those vital services. Promoting greater access to employment, housing, and healthcare will also be key in our efforts.

The Unlock the Waiting Lists! Campaign was a successful advocacy coalition in the early 2000's. Under the administration of Governor Sonny Perdue, Unlock advocated for over 3,000 new Medicaid waivers for people with developmental disabilities, and Georgia invested approximately \$100M in state and federal dollars into services over a multi-year period. Without the support of Governor Perdue and the Georgia General Assembly, this could not have been achieved. There are countless families that benefited from that investment.

As Unlock 2.0, we support the critical work of this Committee and offer the following recommendations to further strengthen home and community-based services in Georgia:

Fund 1,000 new NOW/COMP waivers in the FY24 budget. The increase of 513 new waivers in the FY 23 budget is an encouraging step in investing in individuals and families across the state. Unlock 2.0 recommends an additional increase to 1,000 waivers in the FY 24 budget. This number is based upon the number of students graduating from high school annually, along with the approximate number of caregivers over the age of 65.

Increase starting wages for I/DD Direct Support Professionals to \$15.00 per hour.

The median hourly wage for Direct Support Professionals in Georgia averages \$10.07 per hour. This coupled with a turnover rate at 46.7% creates a dire situation for people that need support for health, wellness, and safety. To help to stabilize the I/DD infrastructure, Unlock 2.0 supports the increase of wages for Direct Support Professionals to \$15.00 as a starting place, with the acknowledgement that to be competitive with other industries, the wages need to be increased over time.

A cost-of-living adjustment (COLA) for I/DD Service Providers. A COLA would serve as a basic assurance for services providers to help keep up with inflation and the rising cost of doing business. The cost of benefits, like insurance, increase annually, and are needed to retain quality staff. A COLA is a rational way to help ensure consistency and employee retention, which are both tied to quality outcomes for persons with I/DD.

Develop a new multi-year plan to address the NOW/COMP waiting list that includes a timeline and measurable outcomes. At the request of the 2016 Georgia General Assembly, DBHDD created a Multiyear Planning List Strategic Plan to help reduce and eliminate the planning lists. We are unaware of specific action taken on 2017 plan and recommend this committee revisit the DBHDD report to help inform the development of a new multi-year plan. We suggest the plan include outcomes to reduce the waiting list by a specific number or percentage annually.

Request pertinent data points from DBHDD on the 7,000 individuals on the I/DD waiting list. To best understand the individuals waiting for services, we believe that age, county, race, ethnicity, gender, and application date are all critical data points for planning and analysis. The length of time on the waiting list might serve as an indicator of immediate and future demand for waiver services and help guide further discussions. Waivers are awarded not on a first come, first serve basis, and are based on "most in need". DBHDD uses an assessment tool to capture the need for services. We recommend asking for more information on the use of this tool and its effectiveness in determining the overall needs of an individual.

Thoroughly consider the impact of managed care for people with I/DD. As a coalition, Unlock 2.0 is concerned about the possibility of a managed care plan for people with I/DD. If this option is being considered, we suggest further study that includes lessons learned from other states that have implemented this model of care for the same population, and for the inclusion and input from providers, families, and other stakeholders in the process.

Because of the strain and continuing challenges brought on by the COVID pandemic on the I/DD community, we support the work of the committee to help bring much need relief and actionable plans for the future. We look forward to working with you on viable solutions that benefit Georgians with I/DD and support them to thrive in their communities.

Signed,



Statewide
Independent Living
Council of Georgia

